

DRAFT BACKGROUND FOR THE NATIONAL PLAN TO ADDRESS ALZHEIMER'S DISEASE

National Alzheimer's Project Act and Requirement to Develop a National Plan

On January 4, 2011, President Barack Obama signed into law the National Alzheimer's Project Act (NAPA), requiring the Secretary of the U.S. Department of Health and Human Services (HHS) to establish the National Alzheimer's Project to:

- Create and maintain an integrated national plan to overcome Alzheimer's disease (AD).
- Coordinate AD research and services across all federal agencies.
- Accelerate the development of treatments that would prevent, halt, or reverse the course of AD.
- Improve early diagnosis and coordination of care and treatment of AD.
- Improve outcomes for ethnic and racial minority populations that are at higher risk for AD.
- Coordinate with international bodies to fight AD globally.

The law also establishes the Advisory Council on Alzheimer's Research, Care, and Services and requires the Secretary of HHS, in collaboration with the Advisory Council, to create and maintain a national plan to overcome AD.

NAPA offers an historic opportunity to address the many challenges facing people with Alzheimer's disease and their families. Given the great demographic shifts, including the doubling of the population of older adults that will occur over the next 30 years, the success of this effort is of great importance to public policy makers, service providers, and people with AD and their family members.

This is a draft framework of broad goals and specific strategies for addressing AD. The final National Plan will include a detailed listing of current federal activities as an appendix and, as directed by NAPA, initial recommendations for priority actions to expand, eliminate, coordinate or condense programs. Addressing AD also will require the active engagement of the public and private sectors, whose input is not yet reflected in this draft. HHS is distributing this background material to complement the draft framework to the Advisory Council on Alzheimer's Research, Care and Services and making it public to obtain input on the priorities for investing resources among the

strategies. At its next public meeting, the Advisory Council will discuss priorities for federal actions and strategies for engaging the private and other public sectors in actions to address AD. Based on this input, HHS will finalize the National Plan and include federal, other public and private actions. The path forward will depend on resources, scientific progress, and focused collaborations among many partners. Over time, HHS will work with the Advisory Council and stakeholders to monitor progress and revise the National Plan.

Alzheimer's Disease (AD)

AD is an irreversible, progressive brain disease that affects as many as 5.1 million Americans.¹ It slowly destroys brain function, leading to cognitive decline (e.g., memory loss, language difficulty, poor executive function), behavioral and psychiatric disorders (e.g., depression, delusions, agitation), and declines in functional status (e.g., ability to engage in activities of daily living and self-care).² In 1906, Dr. Alois Alzheimer first documented the disease when he identified changes in the brain tissue of a woman who had memory loss, language problems, and unpredictable behavior. Her brain tissue included abnormal clumps (amyloid plaques) and tangled bundles of fibers (neurofibrillary tangles). Brain plaques and tangles, in addition to the loss of connections between neurons, are the main features of AD.³

In this plan, the term “Alzheimer's disease,” or AD, refers to Alzheimer's disease and related dementias, consistent with the approach Congress used in NAPA. Related dementias include frontotemporal, Lewy body, mixed, and vascular dementia. It is often difficult to distinguish between AD and other dementias in terms of clinical presentation and diagnosis. Some of the basic neurodegenerative processes have common pathways. People with dementia and their families face similar challenges in finding appropriate and necessary medical and supportive care. Unless otherwise noted, in this plan AD refers to these conditions collectively.

The first symptom of AD is often memory impairment. As the disease progresses, memory continues to decline, and other functions like language skills and decision making become more difficult. Personality and behavior changes may also occur. A person with the disease may no longer recognize family and friends. Eventually, the person who survives with AD is completely reliant on others for assistance with even the most basic activities of daily living, such as eating.^{4,5}

In more than 90 percent of people with AD, symptoms do not appear until after age 60, and the incidence of the disease increases with age. The causes of AD are not completely understood, but researchers believe they include a combination of genetic, environmental, and lifestyle factors.⁶ The importance of any one of these factors in increasing or decreasing the risk of developing AD may differ from person to person. In rare cases, known as early or younger-onset AD, people develop symptoms of AD in their 40s or 50s.

Unless the disease can be effectively treated or prevented, the number of Americans with AD will increase significantly in the next two decades. The number of people age 65 and older in the United States is expected to grow from 40 million in 2010 to 72.1 million in 2030. The prevalence of people with AD doubles for every 5-year interval beyond age 65, and the significant growth in the population over age 85 from 5.5 million to 8.7 million, estimated to occur between 2010 and 2030, suggests a substantial increase in the number of people with AD.

AD places an enormous emotional and financial burden on individuals who have it and their family members. Informal caregivers, such as family members and friends, provide the majority of care for people with AD in the community. Informal caregivers often do not identify themselves as such; they are simply a wife, daughter, husband, son, or friend helping out a person whom they care about. However, the intensive support required for a person with AD can negatively impact the caregiver's health and well-being. Informal caregivers often report symptoms of depression and anxiety, and have poorer health outcomes than their peers who do not provide such care.⁷ When the person with AD moves to a nursing home to receive 24-hour care, the financial costs to families are great: an estimated \$78,000 per year.⁸

Caring for people with AD also places a burden on health and long-term care systems. Individuals with AD use a disproportionate level of health care resources; for instance, they are hospitalized 2-3 times as often as people the same age who do not have the disease.⁹ Similarly, while people living in nursing homes are a small percentage of the older population, nearly half (48 percent) of nursing homes residents have AD.¹⁰ As the number of people with AD grows over the next two decades, this disease will place a major strain on these care systems as well as on Medicare and Medicaid, the major funders of this care.

The Challenges

The National Plan will be designed to address the major challenges presented by AD.

1. While research on AD has made steady progress, there are no pharmacological or other interventions to definitively prevent, treat, or cure the disease.
2. While HHS has taken steps to develop quality measures to assess AD care and to improve the training of the health and long-term care workforce, there is room for improvement.
3. Family members and other informal caregivers, who take on the responsibility of caring for a loved one with AD, need support. The majority of people with AD live in the community, where their families provide most of their care. The constant need to provide care can take a toll, with about one-third of caregivers reporting symptoms of depression.^{10,11}

4. Stigmas and misconceptions associated with AD are widespread and profoundly impact the care provided to and the isolation felt by people with AD and their families.
5. Public and private sector progress is significant but should be coordinated and tracked. In addition, data to track the incidence, prevalence, trajectory and costs of AD are limited.

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